Congratulations on the birth of your NICU strong baby!

All expectant parents anticipate the birth of a healthy full-term baby. Having a baby in the Neonatal Intensive Care Unit (NICU) can cause you to have feelings of frustration, guilt, anger, confusion, anxiety, or sadness. While all of these feelings are normal, try to focus on your baby’s daily accomplishments. Your positive attitude is crucial during this difficult time and will make an enormous difference in your NICU stay and daily interactions with friends, family, and hospital staff. Make the choice every day to try to spend quality time with your baby, focus on his/her progress, be your baby’s best advocate, and show gratitude to others for the support they give your family during your baby’s NICU hospital stay.

The information in this guide is not medical advice and is not a substitute for professional medical care. Always seek guidance from your doctor regarding medical questions that arise during your baby’s NICU hospital stay.
NICU CONTACT INFORMATION
Office Phone:
Fax:
Email:

PEDIATRICIAN CONTACT INFORMATION
Office Phone:
Email:
Doctors in the practice:

NEONATOLOGIST CONTACT INFORMATION
Office Phone:
Email:
Doctors in the practice:

MY BABY’S LOCATION
What is baby’s room number?
______________________________
Who are baby’s caregivers in the NICU?
______________________________

NICU BASICS
○ What is the NICU schedule/routine?
○ What are the hand-washing and gowning procedures?
○ When are visitation hours/restrictions?
○ When do nurses change shift?
○ When are doctor patient rounds?
○ Can siblings visit?

PARKING
○ Where do we park, is it free?
○ Can I call ahead for a wheelchair?

MEALS
○ Are parent meals provided? How many?
○ Are drinks/food allowed in baby’s room?

ACCOMMODATIONS
○ Can we sleep in baby’s room?
○ Is there a Ronald McDonald house?
○ Where else can we stay overnight?

NICU EQUIPMENT
○ Ask questions about any equipment or monitors that you do not understand.

CARING FOR YOUR BABY
Can I do kangaroo care?
○ Yes ○ No Frequency:
Can I change baby’s diaper?
○ Yes ○ No Frequency:
Can I breast/bottle feed?
○ Yes ○ No Frequency:
Can I take baby’s temp.?
○ Yes ○ No Frequency:
Can I give baby a bath?
○ Yes ○ No Frequency:
Can I bring clothes for baby?
○ Yes ○ No Clothing allowed:

HOSPITAL SUPPORT OFFERED
○ NICU parent training sessions
○ NICU support groups
○ External non-profits (High Risk Hope)
○ Social worker, clergy or psychologist
○ Photography session

MEDICAL TESTS AND TREATMENTS
○ What medical tests or treatments could baby need?
○ What are the risks?
○ Will my consent be required?
○ When will I receive the results?

DON’T FORGET THE FUN STUFF!
○ Take photos
○ Record videos
○ Put up photos of your family
○ Make hand/footprints
○ Journal baby’s NICU Stay

PRE-DISCHARGE ITEMS
○ I am comfortable feeding baby
○ I am comfortable bathing baby
○ I am comfortable giving baby meds
○ I know how long to breastfeed or how much to feed baby
○ I know how to mix the infant formula
○ I know how to take axillary (underarm) temp. and how to read the thermometer
○ I know how to use a bulb syringe
○ I know how to perform CPR on baby
○ I have a car seat for baby
○ I know how to use the car seat properly and where/how to position it in my car
○ I have clothes for baby to wear home
○ I have selected health care providers

DISCHARGE QUESTIONS
○ Do you understand baby’s entire stay in the NICU, tests, results, treatments, etc.?
○ Do you understand what problems or conditions may continue after your baby is discharged and how to handle them?
○ Have you discussed your baby’s feeding needs, amounts, and schedule with your doctor?
○ Do you know what follow-up appointments your baby needs and why he/she needs them?
○ Have you scheduled the appointments? If not, do you have phone number(s) to do so?
○ Do you know what medications baby needs and how to administer them?
○ Do you know what monitors baby needs, how they work and who to call if a problem arises?
○ Did you complete a course in CPR?
○ Which immunizations did baby have?
○ What are the results of baby’s hearing and vision screening tests?
○ Do you have a breast pump? Can you rent one from the hospital?
○ Do you know how much stimulation is recommended for baby and what signs to detect if baby is over-stimulated, tired, sick too cold/hot or hungry?
○ Are there any other discharge requirements that must be completed?
○ Is there anything else you want to know or practice before taking your baby home?
Your first visit to the NICU can be a scary and stressful experience. Do your best to familiarize yourself with the equipment and ensure all of your questions are answered by members of the NICU staff. Your first visit is the best time to get to know your baby and begin bonding. The NICU staff will give you the opportunity to interact with your baby in a way that is best for him/her. Some babies will require “minimal stimulation”, which will allow parents to use a firm touch and a soft voice. Others will be more stable and parents will be allowed time to interact with them. Depending on your baby’s condition, you may or may not be able to hold your baby during your first visit.

ANTIBIOTICS Medications given by mouth or IV to help your baby fight infections.

BAGGING When a soft rubber or latex bag and mask are used to fill your baby’s lungs with air and oxygen.

BLOOD GASES A measurement of the amount of oxygen, carbon dioxide, and acid in your baby’s blood drawn from an artery (ABGs, Arterial Blood Gases) or from smaller capillaries (CBGs, Capillary Blood Gases).

CARDIO-RESPIRATORY MONITOR A heart monitor that measures and records some of the baby’s vital functions. This monitor will record the baby’s heart rate, blood pressure and breathing rate. Alarms are set for both high and low rates, so in the event your baby’s vital signs are irregular or abnormal, the monitor will sound. Sometimes there are false alarms for varied reasons. The medical teams at the bedside are skilled in responding to the alarms and finding a solution. The baby is usually placed on the cardio-respiratory monitor until discharged and ready to go home.

CPAP/HFNC Continuous positive airway pressure or “CPAP” provides a steady flow of oxygen through a small face mask or small prongs that fit into the baby’s nostrils.

ET TUBE An endotracheal tube is a small, soft, flexible tube that is passed through the mouth past the vocal cords and into the trachea or windpipe. This process is called intubation. The ET Tube is then connected to a ventilator to assist the baby with breathing. Because this tube passes between the vocal cords, you will not be able to hear your baby’s cry while the tube is in place.

EYE EXAM Completed by an ophthalmologist to see if the blood vessels in the retina have developed normally.

FEEDING TUBE Most premature or sick babies will start feeding by gavage. Gavage feeding is a method where a small, flexible tube called a feeding tube is inserted through the nose or mouth, down the esophagus and into the stomach. Gavage feeds are also referred to as tube feedings. When a tube is placed through the nose and into the stomach, it is referred to as a naso-gastric tube, or NG tube. NG tubes are left in place once a baby begins to bottle-feed, so that the tube does not get in the way of the baby’s tongue. When a tube is placed through the mouth and then goes into the stomach, it is referred to as an oro-gastric tube, or OG tube. It is used for feedings until the baby is strong enough to suck from the bottle or is breastfed.

HEARING SCREEN A test used to check for early signs of hearing problems.

HYPERALIMENTATION Also called Hyperal/TPN/PIA, is a special mix of nutrients and fluids given to babies through a vein when they are unable to be fed nourishment by mouth.

INCUBATOR OR ISOLETTE Many babies in the NICU are unable to maintain their own body temperature and are placed in an incubator. The incubator provides body warmth, humidity and protection from outside stimulation. Portholes allow for easy access without allowing cold air in or heat out.

NASAL CANNULA A nasal cannula is used when a baby needs a steady flow of oxygen to help him/her breathe as opposed to the positive pressure released by a CPAP machine. Soft pliable plastic prongs are placed inside the baby’s nostrils while warm, moist, oxygenated air flows into the nose.

N.P.O. A Latin abbreviation for the order “nothing by mouth.”

NUTRITION Anything that nourishes your baby (breast milk, formula, or IV fluids.)

OPEN CRIB An open crib is a clear plastic bassinet that your baby graduates to when they are close to going home. Preterm infants generally must be medically stable, weigh 1500-1800 grams, and be able to maintain their temperature to graduate to the open crib.

OXYGEN HOOD In the event that your baby is breathing on his/her own, but still needs some respiratory support, an oxygen hood may be prescribed. The hood is made from clear plastic and is placed directly over the baby’s head. The hood is connected to an oxygen source that provides the newborn with supplemental oxygen. Room air contains 21% oxygen. Premature babies may need extra oxygen, and some require pure oxygen.

PAL (PERIPHERAL ARTERIAL) CATHETER A PAL is a catheter placed in an artery in the arm or leg. The purpose of a PAL is to enable the staff to continuously monitor the baby’s blood pressure and to allow them the ability to draw blood for tests and gases without sticking the baby. This is especially important for babies who have breathing problems and are placed on a ventilator.

PHOTOTHERAPY LIGHT In the event that your baby is diagnosed with jaundice, also called hyperbilirubinemia, phototherapy lights are often used. These special “light banks” have bulbs that give off light in the blue spectrum. The lights alter the bilirubin in the skin to a water-soluble form so that the baby can rid the body of extra bilirubin through the urine or stool. Bilirubin is a substance in the blood produced by the breakdown of red blood cells. After applying a soft mask to protect your baby’s eyes, the baby will be placed under the lights to expose the skin to lower his/her bilirubin level. For maximum exposure, babies under phototherapy lights wear diapers only.
PICC (PERIPHERALLY INSERTED CENTRAL CATHETER)
A PICC line is a long, very thin, soft tube made of silicone or polyurethane that is placed in a blood vessel, in the arm, scalp, or leg. The catheter is then moved upward through the body so the tip is in a big, vein near the heart. A PICC is used when long-term medication therapy or IV fluids are needed.

PERIPHERAL IV (PIV) CATHETER
Peripheral IVs are inserted through the skin into a small vein. The IV allows the NICU staff to give your baby fluids, such as sugar solutions and medications. A PIV in a baby is same as in adults, only smaller.

RADIANT WARMER
Your baby may be placed in an open bed warmer immediately following birth to help maintain the body temperature until he or she is medically stable. The temperature probe from the warmer is attached to the baby by a probe cover. The probe senses the temperature of the newborn and adjusts the heat as needed.

SLEEP STUDY
A test done for babies at risk for breathing or heart rate problems. The test helps doctors decide if a home monitor is needed.

ULTRASOUND
A machine that uses sound waves to produce pictures of internal body tissues, such as the head or heart.

UMBILICAL LINES/TUBES (UVC/UAC)
A tiny tube may be inserted in an artery or vein in your baby’s belly button (umbilicus) so that small amounts of blood can be taken for testing without using a needle. This tube also measures blood pressure and may be used to give IV fluids and medicines. While this sounds painful, it is not. There are no nerve endings in your baby’s belly button where the catheter is inserted.

VENTILATOR
A ventilator is a machine attached to the baby’s ET tube which pumps oxygen into the lungs with a controlled pressure that helps the baby breathe.

BOOKS FOR BABIES
Reading to your premature baby is something you can do to help him or her throughout your family’s entire NICU stay. Three separate 2015 studies noted the short and long-term benefits of parents reading (talking or singing) to their premature baby in the NICU. A Brown University study found that exposing premature babies to more adult language in the NICU can increase their language abilities at 7 and 18 months (adjusted age), which is the building block for future reading and success in school. A Vanderbilt University study showed that premature babies who received an interventional therapy combining their mother’s voice and a pacifier-activated music player learn to eat more efficiently and have their feeding tubes removed sooner than other preemies, which correlated to shorter NICU stays for the babies. A Harvard University study found that the sound of a mom’s voice boosts brain growth and development in premature babies. HRH’s Books For Babies program ensures parents of every baby born prematurely in the hospitals HRH supports will receive a book to read to their baby.

“Young doesn’t always roar. Sometimes courage is the quiet voice at the end of the day saying, ‘I will try again tomorrow.’”
—Mary Anne Radmacher
Get to know the NICU doctors, nurses and staff, specifically your baby’s care team. Your medical team is an integral aspect of your baby’s treatment, but do not underestimate the role you play as the captain of this critical team. It is your right and responsibility to ask difficult questions, demand adequate answers, request second (and even third) opinions, and ultimately make the final decisions for your baby. Always remember that you are your baby’s biggest advocate and will make the right decision on their behalf.

NICU STAFF MEMBERS

NEONATOLOGIST A pediatrician (children’s doctor) with advanced training in the care of sick newborns. The neonatologist who is in charge of the NICU is sometimes called the “attending” doctor. There may be several neonatologists in the NICU.

NEONATOLOGY FELLOW A fully-trained pediatrician who is receiving advanced training in the care of sick and premature babies.

NURSE OR RN A health professional who has passed a written examination after graduating from a college or hospital nursing program.

OCCUPATIONAL THERAPIST (OT) A health professional who helps evaluate a baby’s neurosensory development. (“Neurosensory” refers to the baby’s nervous system.) The OT focuses on feeding and swallowing issues, range of motion in the arms and legs, and developmental positioning.

SOCIAL WORKER A professional who is specially trained to help you cope with the emotional aspects of your baby’s NICU stay. The social worker can help you obtain the information you need from your baby’s doctors, provide you with sources of information on your baby’s medical problems, help you deal with financial difficulties and stress, and help you make any special arrangements you may need for your baby’s discharge and follow-up care.

RESPIRATORY THERAPIST A health professional trained to care for babies with breathing problems and to use the medical equipment needed to care for these babies.

TECHNICIANS Staff members who perform specific procedures such as drawing blood or taking x-rays.

NEONATAL NURSE PRACTITIONER A registered nurse who has advanced education (usually a master’s degree) and specialized training in working with premature and sick newborns. He or she works under the direction of the neonatologist, can perform many procedures, and helps direct your baby’s care.

PEDIATRIC RESIDENT A doctor who is receiving training in the medical specialty of pediatrics.

NEONATAL CLINICAL NURSE SPECIALIST A neonatal nurse with advanced training who works under the supervision of the neonatologist and who cares for sick and premature babies.

PHYSICAL THERAPIST (PT) A health professional who helps evaluate how a baby moves and how any movement problems may affect milestones like sitting, rolling over or walking. The physical therapist aims to improve muscle strength and coordination.

REGISTERED DIETITIAN (RD) An expert in nutrition who has a four-year college degree. RDs have passed a national examination administered by the Commission on Dietetic Registration. Registered dietitians who work in the NICU also have had additional training in nutrition for children. RDs work with the neonatologists and nurses to help make sure your baby is receiving all the nutrients needed for healthy growth.

SPEECH AND LANGUAGE PATHOLOGIST A person who is trained in speech and language problems. He or she often works with newborns in NICUs to help assist them with feeding problems.

HOSPITAL VOLUNTEERS If your NICU permits volunteers to interact with babies, ensure your nurse documents whether you will allow volunteers to have contact with your baby when you’re away.

LACTATION CONSULTANT A professional breastfeeding specialist trained to teach mothers how to feed their baby.
Our Mission
High Risk Hope is a 501(c)(3) for purpose organization that provides support, encouragement, information and resources to women and families who are experiencing a high risk pregnancy resulting in hospital bed rest, potential premature birth and neonatal intensive care after delivery.

Contact HRH
Headquarters
1702 N. Avenida Republica de Cuba
Tampa, FL 33605
813.247.5483
info@highriskhope.org
www.highriskhope.org
www.tottrot.org

“Where there is love there are always miracles.”
—Willa Cather

“What counts is not necessarily the size of the dog in the fight—it’s the size of the fight in the dog.”
—Dwight D. Eisenhower

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HRH is a catalyst in the global fight to end premature birth, winning a life-long victory with every baby we help.

WELCOME TO THE HRH FAMILY, NOW THAT YOUR BABY IS #NICUSTRONG FIND US ONLINE AND GET INVOLVED

SHARE YOUR BABY’S STORY & PHOTOS
SIGN UP FOR THE TOT TROT IN NOVEMBER
TAKE OUR ONLINE PATIENT SURVEY
LIKE US ON FACEBOOK, INSTAGRAM, & TWITTER

HRH PATIENT STORY
Theo Carbone

Emily Carbone’s water broke when she was 20 weeks pregnant, and she was placed on complete hospital bed rest where doctors monitored her constantly. Theo was born three weeks later weighing 1 pound 8 ounces. The delivery room was silent – Theo was not crying and the NICU team quietly worked to prepare Theo for his transport to the NICU. Several hours later Emily met Theo and was overcome with joy at the sight of the baby she fought so hard for!

The Carbone family’s NICU journey was filled with highs and lows, where they learned how to feed Theo, make him feel comfortable, and connect with him despite the cumbersome equipment necessary for his survival. After 113 days in the NICU, Theo went home to his family! His parents were anxious because he came home on oxygen, a pulse oximetry, and apnea monitor. They quickly learned how to work with the devices and feel confident in their parenting abilities. Slowly but surely, Theo got stronger and healthier. Although Theo still works to catch up in certain areas of development, he is thriving! The Carbone family is proud of Theo’s strength and determination to survive. He never gave up and neither did his parents who received the greatest gift, a healthy baby boy.